A Systematic Review of Indigenous Caregiver Functioning and Interventions

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A report submitted in partial requirement for the degree of Master of Psychology (Clinical) at the University of Tasmania.

Statement of Originality

I declare that this thesis is my own work and that, to the best of knowledge and belief, it does not contain material from published sources without proper acknowledgement, nor does it contain material which has been accepted for the award of any other higher degree or graduate diploma in any university.

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Abstract

The global population is aging with concomitant and exponential growth in chronic, degenerative illnesses that require long-term intervention and support. The majority of these support needs are met by informal family caregivers. While there have been three decades of research focusing on caregivers generally, the extent to which research has focused on indigenous caregivers is unclear. Worldwide, indigenous peoples face severe economic and health disadvantages that may make them even more vulnerable to the negative aspects of informal caregiving. The current systematic review aimed to synthesize the extant literature on indigenous caregiver functioning and the interventions that are efficacious in alleviating indigenous caregiver distress. Inclusion criteria were peer-reviewed quantitative studies examining indigenous caregiver functioning or evaluating indigenous caregiver interventions. A total of 892 records were located; however only five studies met the inclusion criteria. Four of the five studies contained numerous methodological weaknesses that compromised the reliability and credibility of their findings. Future research in this area would benefit from greater adherence to the standards of research that contribute to a strong and reliable evidence base.

Public health concerns are often focused on the effect of disease and disability on sufferers; however, there are also substantial impacts on those who provide unpaid assistance to people with a disability, chronic condition, terminal or mental illness or difficulties associated with old age (ABS & AIHW, 2008; Cummins et al., 2007). The global population is aging and this has been accompanied by a shift in the burden of disease from acute, communicable diseases to chronic, degenerative illnesses that require long-term intervention and support (World Health Organization, 2011a). The majority of these support needs are met by informal family caregivers, particularly in the absence of established and affordable long-term care infrastructure, but also in countries with relatively well-developed systems of formal support (WHO, 2011b). While informal caregiving represents a considerable economic saving for society (AARP, 2007; Access Economics, 2012), it often comes at a cost for caregivers. It is associated with various negative outcomes in terms of diminishing caregivers' physical and psychological health, restricting their ability to participate in social and economic activities, and reducing their capacity to attend to their own health needs (Cummins et al., 2007; Pinquart & Sörensen, 2003). Among the general population, these effects are generally worse when caregivers have pre-existing poorer health and fewer economic resources (Pinquart & Sörensen, 2005). In this regard, certain groups, such as indigenous carergivers, may be particularly susceptible to the negative effects associated with caregiving.

Indigenous peoples are culturally distinct groups that form a non-dominant sector of society and have historical continuity with pre-invasion and pre-colonial ancestral roots and lands (Behrendt, 2009). Worldwide, indigenous people have lower life expectancy, poorer health, lower participation in education and employment and lower income compared to the general population (Cooke, Mitrou,

Lawrence, Guimond, & Beavon, 2007; Freemantle, Officer, McAullay, & Anderson, 2007; Office for Disability Issues and Statistics New Zealand, 2010). While the disparity in life expectancy between indigenous and non-indigenous peoples has decreased over the past 20 years, increased longevity has been accompanied by a greater burden of disease and disability (Cooke et al., 2007; Cotter, Anderson, & Smith, 2007; Hayward & Heron, 1999; Indian Health Service, 2013; Office for Disability Issues and Statistics New Zealand, 2010; Zhao, Condon, Guthridge, & You, 2010). However, compared to non-indigenous carers, indigenous caregivers face the growing disease burden from a more vulnerable position, with poorer health and fewer resources available to support them in their roles (Edwards, Gray, Baxter, & Hunter, 2009).

The economic and health disparities between indigenous peoples and the general population appear to be worse among people with caregiving responsibilities. For example, in Australia, indigenous caregivers are more likely to experience greater financial stress, with respect to higher unemployment, lower income and fewer household resources, compared to non-indigenous caregivers (ABS & AIHW, 2008; Hill, Thomson, & Cass, 2011). The health status of indigenous caregivers in Australia is also poorer than that of non-indigenous caregivers, with around seven per cent of indigenous caregiver requiring help with core activities. This proportion is between one and a half to three times higher than the proportion of non-indigenous caregivers who need assistance (ABS & AIHW, 2008). In addition, the added financial strain associated with being a caregiver that is apparent in the general population, is also evident within indigenous populations. For example, among Indigenous Australians, caregiver status is associated with lower income and poorer household resources compared to those without caregiving

responsibilities (ABS & AIHW, 2008). Being a caregiver is also associated with differences in employment capacity, with more caregivers than non-caregivers being employed in part-time instead of full-time work (44% and 37% respectively). In this context, the disability and carer's pension may constitute an essential contribution to indigenous household incomes (Burns, 2012; Hill et al., 2011). Thus, indigenous caregivers may experience double jeopardy, faced with the disadvantages, stressors and difficulties associated with being both indigenous and a caregiver.

In countries such as Australia, the last three decades has brought an increased governmental focus on the needs of caregivers in general (e.g., the National Respite for Carers Program and the Aged Care Act 1997); however there remains a distinct lack of information about the needs and outcomes of indigenous caregivers. In the last five years there have been two narrative reviews about carers' adjustment that have included indigenous carers in the scope of their report. In 2007, the Australian Department of Health and Aging (DOHA) commissioned a report intended to identify the needs of Australian caregivers (Eagar et al.; Williams & Owen, 2009). This report involved 230 Australian and international sources of information. The authors reported that in the interest of capturing all of the available knowledge, the report was not a systematic review, and therefore included diverse information derived from practice literature, opinion pieces, surveys, summaries of secondary source material, anecdotal accounts and policy documents. This approach acknowledges the difficulties in applying "Cochrane-style" standards for evidence in fields other than medicine. The difficulty with this less discriminating approach is that the full extent of the credible evidence-base remains unclear. This review is also limited by its unclear and inconsistent reporting. For example, in the executive summary under the heading the "Effectiveness of interventions for specific types of

carers and specific types of care recipients" (Eagar et al., 2007, p. iv) the authors noted only a single study that focused on indigenous carers. However, they acknowledge that the study examined the need for services, rather than the effectiveness of any particular intervention. The inclusion of such a broad scope of information source, combined with the unclear reporting and minimal critique of the material, does little to elucidate indigenous caregiver functioning and support needs.

Carers Australia (the peak national body representing carers) recently also produced a literature review. Unlike the DOHA report, the *Carers Australia* review focused solely on indigenous carers and aimed to redress the lack of knowledge about the experiences and outcomes for Indigenous Australian caregivers (Taylor, 2013). The author suggests Indigenous Australian caregivers experience considerable caregiving burden and distress. However, this review was also not a systematic review. The eligibility criteria for the review were broad and included a range of study types with varying degrees of methodological rigour. Further, the review did not provide any explicit description and evaluation of these information sources and consequently drew some conclusions on the basis of very weak levels of evidence (Merlin, Weston, & Tooher, 2009; NHMRC, 2000a, 2000b). For example, the findings regarding the role and functioning of male indigenous caregivers were based on a single journal article (Pearce, 2000) that provided only an anecdotal account by a male indigenous carer about his experiences. This clearly limits the representativeness required to draw conclusions about indigenous male carers' experiences or needs beyond this one viewpoint. While the review did include one randomised control-trial (Korn, 2009) there was no methodological critique of the study to assist in evaluating the experimental rigor and thus the level of risk for bias

in the results (Campbell, Piaggio, Elbourne, & Altman, 2012). This is problematic as it limits the confidence that can be placed in the review's conclusions.

In the last seven years there have been a number of qualitative studies undertaken with indigenous carers. Studies include sample sizes that range from 3 to 33 and have been conducted with indigenous peoples of Canada, United States of America, New Zealand and Australia. The findings indicate that indigenous caregiving may be accompanied by psychological distress (Corbett, Francis, & Chapman, 2006; Dyall, Feigin, & Brown, 2008; Emden, Kowanko, de Crespigny, & Murray, 2005; McGrath, 2008; Smith et al., 2011; Ward, Jowsey, Haora, Aspin, & Yen, 2011). In a study that included 19 Australian Aboriginal caregivers, McGrath (2008) found that exhaustion and frustration were experienced by those providing informal care. Similarly, Ward et al. (2011) found reports of emotional exhaustion amongst the three Aboriginal and Torres Strait Islander caregivers they interviewed. There have been very few studies that have compared distress in indigenous caregivers across cultures. Anngela-Cole & Busch (2011) conducted a qualitative study that compared caregiver functioning across four cultural groups (14 European Americans, 13 Chinese Americans, 17 Japanese Americans and 12 Native Hawaiians). They found that European American caregivers reported high levels of stress relative to the other three groups. The researchers speculated that the reasons for the lower levels of relative distress reported by the other three groups were related to cultural expectancies. While the Chinese and Japanese American caregivers acknowledged the stress they were feeling to some extent, they also stated that there were strongly held cultural norms against disclosing distress. In earlier research on cross-cultural caregiving, Anngela-Cole and Hilton (2009) suggest that for some cultural groups, such as Japanese Americans, caregiving may be

conceptualised as an obligation enforced by fear of social shame. In contrast, Anngela-Cole and Busch (2011) concluded that the Native Hawaiian caregivers were socialised to perceive caregiving in a more positive light and as a normal and commonplace part of life. In summary, there seem to be few studies that have attempted to compare cultural groups. The presence of objective stressors, such as personal care assistance, medication management, transportation, and inadequate caregiver knowledge seem to be common across all caregiver groups (Anngela-Cole & Busch, 2011; McGrath, 2008). Beyond these factors however, the findings from Anngela-Cole and Busch (2011) tentatively suggest there may be heterogeneity in levels and causes of distress across culturally diverse indigenous groups. Future research should attempt to understand cross-cultural differences in the genesis of these issues as this has direct implications for interventions that are culturally appropriate.

While most qualitative studies, and the two reviews to date, suggest there is high burden associated with care giving for indigenous carers there is some research that explores the positive aspects of caregiving. Across indigenous peoples there may be common protective factors that might buffer stress, such as cultural beliefs and values that normalise and facilitate caregiving within the extended family structure (Anngela-Cole & Busch, 2011; Crosato, Ward-Griffin, & Leipert, 2007; Evans-Campbell, Fredriksen-Goldsen, Walters, & Stately, 2005; Hennessy & John, 1995; McGrath, 2008; Smith et al., 2011). For example, Crosato et al. (2007), in a sample of 13 Canadian Aboriginal women, found that the values of family obligation and interdependence were associated with the privileging of caregiving responsibilities over competing priorities. Hennessy and John (1995) also reported strong feelings of family obligation and reciprocity toward elders among their sample of 33 Pueblo

Indian caregivers. Further, in a sample of 32 Australian Aboriginal caregivers, Smith et al. (2011) found that older people were seen as providing a valuable connection and link with pre-colonial cultural knowledge, such as language. In addition, among 22 American Indian caregivers, caregiving was described as an affirmation of their role within their cultural group (Evans-Campbell et al., 2005). Therefore, for indigenous people, caregiving is also satisfying and viewed as an important way of expressing and maintaining cultural identity (Crosato et al., 2007; Evans-Campbell et al., 2005; Hennessy & John, 1995).

One possible distinguishing factor for those who do experience caregiver stress is the burden of on-going and multiple caregiving responsibilities (Emden et al., 2005; Hennessy & John, 1995; Smith et al., 2011). In a sample that included an unspecified number of Australian Aboriginal caregivers, Emden et al. (2005) noted feelings of overburden and reduced well-being were associated with constant carergiver responsibilities. For some, this involves caring for more than one person with disease or disability, but also includes care responsibilities for children or grandchildren (Smith et al., 2011). Professional care workers may be particularly vulnerable to the challenges of constant care responsibilities, facing demands both at work and home (Emden et al., 2005). The caregiving stress associated with numerous caregiving demands may be linked to the degree to which the load can be shared among family members (Crosato et al., 2007; Hennessy & John, 1995, 1996; Hennessy, John, & Anderson, 1999; Smith et al., 2011). For example, Hennessy and John (1996) reported that caregiver functioning appeared linked to success in recruiting the assistance of family members in a sample of 33 Pueblo Indian caregivers.

Lack of respite for the primary caregiver is another salient feature of those reporting distress (Hennessy & John, 1996; McGrath et al., 2006; Smith et al., 2011). There are a number of reasons that indigenous caregivers do not get reprieve from caregiving responsibilities including a strong sense of empathy for the care recipient's desire to stay at home (Hennessy & John, 1995; Smith et al., 2011); a belief that the obligation to the care recipient must override personal needs (Ward et al., 2011); belief that service providers cannot provide appropriate care (Crosato et al., 2007); and general lack of access to respite services (McGrath et al., 2006), particularly ones that are deemed cultural safe (McGrath, 2008). Without respite from caregiving, indigenous caregivers can become disconnected from the economic, social and cultural activities that might sustain them in their role (Corbett et al., 2006; Dyall et al., 2008). For example, Corbett et al. (2006) reported that the three Maori caregivers in their study experienced frustrations associated with their limited ability to participate in the life of the Maori community due to caregiving responsibilities. In another sample of eight Maori caregivers, the duties of informal caregiving were linked with restricted participation in school and community activities (Dyall et al., 2008)

While qualitative data provides a rich and meaningful description of indigenous caregiver functioning, it is difficult to synthesise due to the heterogeneity of small, non-representative samples and the idiosyncratic results of qualitative data analysis. Furthermore, qualitative studies do not provide normative data about the clinical significance of mood or other disorders, prevalence data about indigenous caregiver distress, or information about the efficacy of interventions. Rigorous assessments of evidence are increasingly used to develop best practice standards and guide policy and funding decisions in Australia and internationally (Australian

Psychological Society, 2010; Merlin et al., 2009). Thus, the aim of the present investigation was to address the limitations of previous research and reviews and provide a rigorous examination of the quantitative evidence regarding indigenous caregiver functioning and the interventions that are used to support this population.

Method

Included studies had to employ quantitative methods, and be either assessment or intervention studies. The inclusion criteria for the review were studies that

i) focused solely on Indigenous caregivers, or reported outcomes specific to this subgroup;
ii) were peer-reviewed and included a validated outcome measure for some aspect of caregiver functioning (e.g., caregiver burden);
iii) were published in English.

Exclusion criteria were studies that

i) involved caregiver samples who were either the natural or foster parents of children, where the caregiving experiences consisted of typical parenting demands;
ii) exclusively used service providers' or other non –carer informants' reports;
iii) only used caregiver reports to inform the care recipient or patient experience;
iv) did not report data from Indigenous participants separate from non-Indigenous carers' data;
v) were non peer-reviewed.

An electronic search was conducted of the major psychological, medical and indigenous databases: *PsychINFO*, *PubMed*, *Web of Knowledge*, *Scopus, Informit*, *Google Scholar*. Key word searches using the following terms were employed: indigenous or aborigin* or "torres strait" or native* or "first nations" and carer* or caregiv*.The reference sections of articles meeting the inclusion criteria were searched and followed up to ensure that no relevant studies were missed. References in the grey literature (informally published written material) including reports and conference proceedings were also searched for relevant studies. Where necessary, authors were contacted directly to enquire about the existence of full-text reports of studies that may or may not have been published. The results from the search of electronic databases and other sources were imported to Endnote X5 bibliographic software.

The titles and/or abstracts were read to determine potential eligibility. Following this screening process, the full text of the remaining studies were read and checked against the inclusion and exclusion criteria. Those studies meeting the inclusion criteria were examined against the CONSORT guidelines for RCTs (Moher et al., 2010), TREND guidelines for non-randomized designs (Des Jarlais, Lyles, & Crepaz, 2004), and Kelley et al.'s (2003) good practice in reporting survey research.

Results

Figure 1 displays a flowchart of studies that were screened, assessed for eligibility, and included in the review. The combined electronic and other searches yielded 1029 studies including 137 duplicates. Once duplicates were removed, the titles and abstracts of the remaining 892 studies were read to identify studies that potentially

met the inclusion criteria. This screening process resulted in the exclusion of 756 studies.

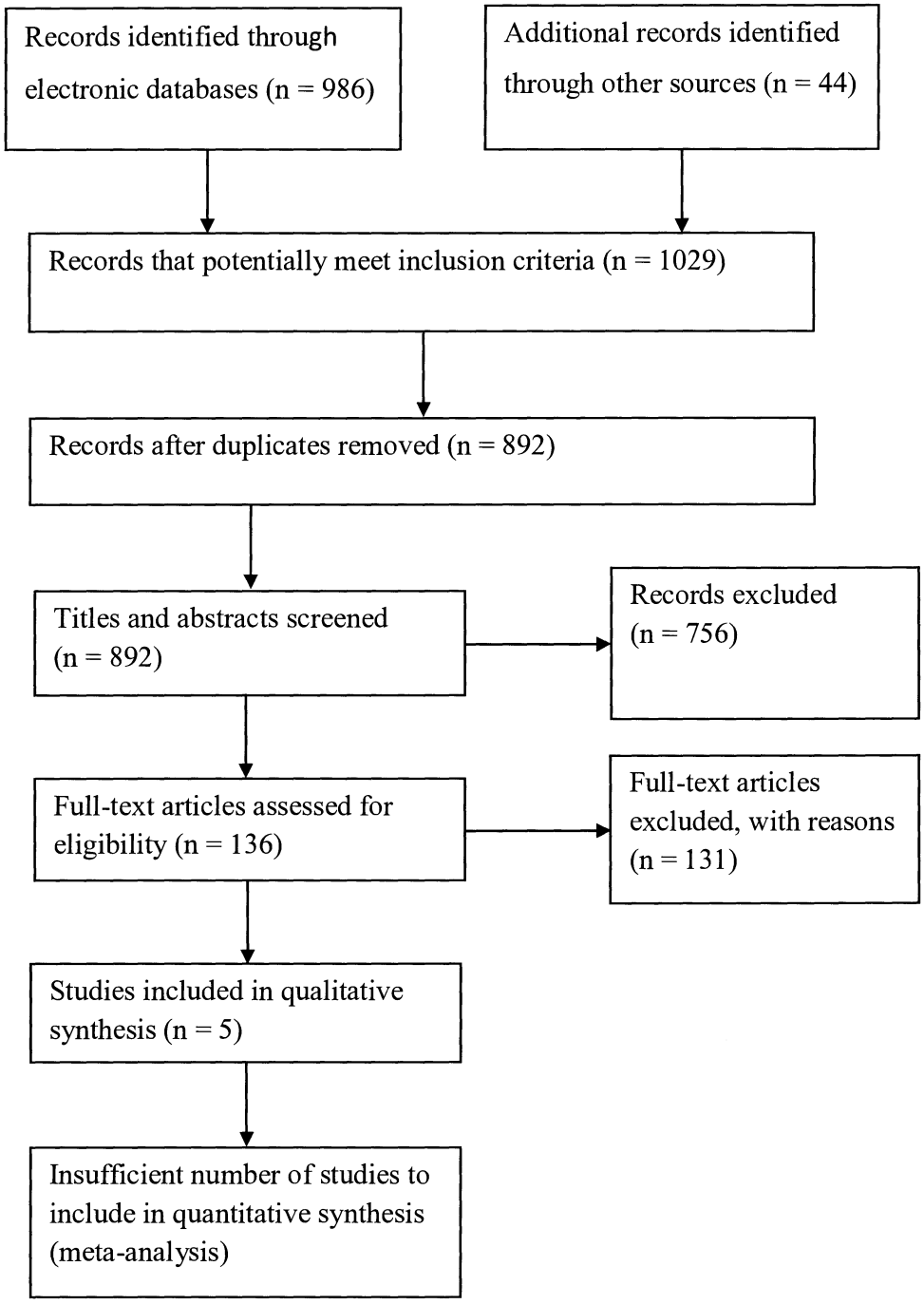

Figure 1. Flowchart of study selection. Adapted from (Moher, Liberati, Tetzlaff, & Altman, 2009).

A large proportion were excluded due to a focus on indigenous foster carers, and indigenous caregiver reports on child health, child development issues and patient health. Full-text review of the remaining 136 studies that appeared to meet the inclusion criteria resulted in 62 being excluded because the studies did not report any outcomes for caregiver functioning. A further 22 articles were excluded because they contained general commentary of indigenous caregiver issues rather than reported the findings of a study. Twenty-two studies did not have indigenous participants or did not report separate data for the indigenous participants in the sample. Eleven studies were project reports and had not been subjected to a peer-review process required for journal publication. Three studies were conference proceedings and no full-text publication existed. Eleven studies about indigenous caregiver functioning used solely qualitative methods. This left four studies that met inclusion criteria; three of which were descriptive studies and one which was an intervention study. Given the small number of quantitative studies located it was not feasible to conduct a meta-analysis. A full list of articles that were excluded after full-text reading, and reasons for their exclusion, can be found in Appendix A.

Table 1 summarises the characteristics of the three studies employing quantitative methods to explore indigenous caregiver functioning. Two publications were located that reported on data from the same cross-sectional study of 13 Aymaran (one of the indigenous peoples of Chile) caregivers, in relation to their caregiver burden (Caqueo-Urizar, Gutierrez-Maldonado, Ferrer-Garcia, & Darrigrande-Molina, 2012) and coping (Caqueo-Urizar, Gutierrez-Maldonado, Ferrer-Garcia, & Miranda-Castillo, 2012). The use of a non-indigenous comparison group (n = 31) allowed for discrimination of the potential factors related to indigenous status that may drive differences in caregiver functioning. In both reports

the authors did not provide sufficient detail about the sampling procedure to assess for the external validity of the findings. Specifically, there was no mention of a random sampling technique, nor was there an indication of the response rate or any exploration of the potential differences between respondents and non-respondents. In the report on caregiver burden, the data analysis was not specified and it is unclear whether a single or multiple analyses were conducted. This means it is difficult to make a judgement about the control of Type 1 error rates. The report on caregiver coping provided details on the Family Coping Questionnaire (FCQ) that are inconsistent with the version of the FCQ that is referenced in the report, with no description or justification of version that was employed in the study. Further, the authors drew unsupported conclusions from the results of the statistical analysis, claiming that a result of $p = .06$ is sufficient to assert a statistically significant difference in the use of a particular coping strategy. The methodological problems of the study and published reports undermine the reliability of the study's findings that Aymaran caregivers experience significantly more overall burden and feelings of incompetence than non-Aymaran caregivers, and use a similar range of coping strategies.

Jervis, Boland, and Fickenscher (2010) employed mixed methods to cross-sectionally examine functioning among a population of reservation-dwelling American Indian caregivers of the elderly. The focus on caregiver function was part of a larger study investigating the cognitive functioning of Native American elders and as such, the sampling for this bigger study was extensive, capturing 83% of the reservations older residents. However, less than half of this sample gave permission for their family caregivers to be contacted and the authors provide no exploration of the differences between those who and those who did not provide this consent. It is

possible that the caregivers of care recipients who gave permission could vary in important ways from those who did not give permission. The authors did compare the cognitive functioning of care recipients' with a participating caregiver and those without, and found no significant differences. This controls for an important source of bias as the negative effects of caregiving are generally worse amongst those caring for people with dementia compared to those caring for a nondemented older adult (Pinquart & Sörensen, 2003). Two standardised assessment instruments were used to measure caregiver burden and caregiving reward (Zarit Burden Inventory and Positive Aspects of Caregiving, respectively). The authors omitted summary statistics of these measures that would facilitate comparisons with other samples or groups. The authors reported that they chose a sample size of 20 and noted that this was an insufficient size to conduct significance testing. This approach circumscribes the usefulness of the quantitative data in elucidating the factors that contribute to caregiver stress or satisfaction. The authors' descriptions of the data suggest that the indigenous caregivers in their sample experienced low levels of burden and stress. The only frequently endorsed burden-related items pertained to thoughts and feelings that the caregiver could do more or do a better job at caregiving. The high endorsement of these guilt items is not clarified by the study's qualitative data. However, the authors suggested that the relatively low endorsement of the other burden items may have been linked to the low level of assistance required by care recipients, living close to care recipients, the lack of competing priorities, and the presence of multiple caregivers. The authors also reported that the caregivers experienced very high levels of the positive aspects of caregiving. Six of the 11 items relate to feeling useful, needed, appreciated, confident, important and good. The other five items relate to skills, outlook on life and relationships. The qualitative

data suggest that the satisfaction with caregiving is associated with an exchange in which the caregiver's assistance is met with the emotional reward of being appreciated. The quality of the relationships may help explain the potency of this exchange: several caregivers reported genuinely enjoying the company of older people and feeling emotionally close to them.

The dimensions of caregiver burden among an indigenous population were explored quantitatively through factor analysis by John, Hagan Hennessy, Dyeson, and Garrett (2001). This cross-sectional study involved a large sample of 169 Pueblo Indian caregivers that was expected to be representative of the indigenous community of interest. The authors report several steps that were taken to adapt the assessment tool (Zarit Burden Interview) and data collection to suit the cultural requirements of the sample. For example, use of a consistent response format across items, reference to the specific care recipient (e.g., 'your mother') instead of the generic 'your relative', and verbal administration of the items by interview rather than the self-report format. The authors clearly described and justified the use of exploratory factor analysis to determine the dimensional nature of caregiving burden amongst the indigenous sample. Four dimensions with high internal consistency (α = 0.79 – 0.88) were suggested by this analysis: role conflict, general negative feelings about the situation, concerns about caregiver efficacy and guilt. Role conflict refers to the degree to which caregiving interferes with other roles or interpersonal relationships. Negative feelings about the caregiving situation and toward the care recipient were also apparent, results that are inconsistent with the qualitative findings from other studies. John et al. (2001) suggest that this may be a methodological concern; the focus groups sometimes used in qualitative studies require participants to voice their opinion amongst peers. In this group context, strong cultural

expectations may not encourage honest reporting of negative feelings about caregiving responsibilities. Caregiver efficacy measures the self-assessed capacity to provide adequate care and is often reflective of crisis in the caregiving situation. Guilt refers to caregivers' feelings of inadequacy regarding the extent and effectiveness of their caregiving. Across all burden items the indigenous caregivers in this sample reported substantial levels of perceived burden. The authors did not provide summary statistics about the level of each dimension of burden in their sample, which limits comparisons with other samples.

Only one intervention study for indigenous caregiver distress was found and it is summarised in Table 2. Korn et al., (2009) examined the efficacy of polarity therapy compared to an enhanced respite control condition in a sample of 38 Native Indian and Alaskan Native caregivers. Polarity therapy, as described by the authors, is a type of biofield touch therapy, which involves applying manual pressure on soft tissue points, against vertebral areas and on opposing left-right locations simultaneously. Polarity therapy is theorised to work by unblocking and balancing energy flow. The enhanced respite control involved engagement in an activity of the individual's choosing with transport, admission costs and supplies provided. For both conditions, a period of three hours of paid care respite was provided for the care recipient. The authors reported that the treatment group improved significantly more than the control group on the primary outcome measure of perceived stress, and on the secondary outcomes of depression, bodily pain, vitality and general health. However, there are several methodological concerns that qualify the conclusions that can be drawn about the efficacy of polarity therapy as an intervention for indigenous caregivers. First, some of the reported intervention effects may be attributable to inflation of Type I error rates, as the study involved a large number of analyses

conducted on potentially highly correlated variables. While stress and depression were assessed with independent measures, the other three significant outcome variables, bodily pain, vitality and general health are subscales of the Short Form (SF)-36. This Type I error risk can be controlled by using a correlation matrix to check for multicollinearity and running a MANCOVA for highly correlated variables. Further, Korn et. al., did not report any effect sizes to assist in determining the practical importance of the treatment effect. A comparison of the change scores in each measure relative to its respective standard deviation gives some indication of the treatment effect size. According to this alternative method, the relative efficacy of the treatment over the control condition was small. In addition, the demographic data suggests that the treatment group may have been significantly older than the control group; however, no preliminary comparisons were made between the groups on the demographic characteristics. Further, age was omitted as a covariate in the multivariate analyses that were conducted to control for the effects of confounding variables. Significant variation in the age of the caregivers could have been expected to influence caregiver stress, as younger caregivers have been shown to experience greater stress than older caregivers in meta-analytic reviews of caregivers in general (Pinquart & Sörensen, 2003). Furthermore, there was no assessment of treatment expectancies which may have independently driven some of the apparent treatment effect, as well as interacting with age to depress the effect of control condition and artificially inflate the treatment effect. A further methodological weakness was the lack of follow-up assessments after post-treatment. It was also not reported as to whether participants were blinded to whether they were in the experimental or control condition.

Table 1

Summary of cross-sectional descriptive studies of indigenous caregiver functioning

Study	Participants & Procedure				Data Analysis	Outcomes		
	N CGs *N* Ind. CGs *N* Comparison	Care recipient diagnosis	Representative sampling Response/ recruitment rate	Measures	Aim Type	Burden	Coping	Reward
Caqueo-Urizar, Gutierrez-Maldonado, Ferrer-Garcia, and Darrigrande-Molina (2012)	45 13 Aymaran CGs 31 non-Aymaran CGs	Schizophrenia	? ?	Zarit Burden Scale (22-item)	Compare groups Mann-Whitney U	+ Incomp. 0 Burden 0 Rejection + Total		
Caqueo-Urizar, Gutierrez-Maldonado, Ferrer-Garcia, and Miranda-Castillo (2012)	As above	As above	As above	Family Coping Quest.	Compare groups ?		0	

Table 1

Summary of Cross-sectional Descriptive Studies of Indigenous Caregiver Functioning (continued)

Study	Participants & Procedure				Data Analysis	Outcomes		
	N CGs *N* Ind. CGs *N* Comparison	Care recipient diagnosis	Representative sampling Response/ recruitment rate	Measures	Aim Type	Burden	Coping	Reward
John et al. (2001)	169 PI 169 PI none	Elderly	Yes ?	Zarit Burden Interview (22-item)	Determine dimensions of burden Factor analysis	RC, NF, CE, G		
Descriptive studies: Mixed methods								
Jervis et al. (2010)	19 AI 19 AI none	Elderly	No 13.6%	Zarit Burden Interview (12-item) Positive Aspects of Caregiving	? None	#		#

Note. CGs, caregivers; Ind., Indigenous; PI, Pueblo Indian; AI, American Indian; RC, Role conflict; NF, Negative feelings; CE, Caregiver efficacy; G, Guilt; +, significant differences between indigenous group and control; 0, no significant difference between indigenous group and control condition; blank spaces indicate outcomes not measured; ?, indicates not specified; #, reported at the item-level only.

Table 2

Summary of Intervention Studies to Improve Indigenous Caregiver Functioning

Study	Participants & Design				Treatment		Outcomes				
	N CGs	*N* Cond.	Care recipient diagnosis	F/up end point	Sessions No., length (Duration)	Format Components	Stress	Depression	Sleep	QoL	Worry
					Randomised Control-Trials						
Korn et al. (2009)	38 AI & AN CGs	1 INT 1 ERC	Dementia	Post.	8 x 50min (?)	Caregiver-only PT	+	+	0	0	0

Note. AI, American Indian; AN, Alaskan Native; CG, caregiver; INT, intervention; ERC, enhanced respite control; Post., post-treatment; PT, Polarity Therapy; QoL, quality of life; +, significant differences between intervention and control; X, significant difference between conditions at initial follow-up, but not maintained to final assessment; 0, no significant difference between intervention and control condition; blank spaces indicate outcomes not measured; #, indicates control group patients improved across follow-ups; ?, indicates not specified.

In summary, the quality and strength of the studies into indigenous caregiver functioning is weak. There was an absence of guiding theoretical frameworks. All of the studies used cross-sectional designs and most failed to examine differences between potential subjects who eventually participated and those who did not. Further, use of standardised assessment tools was weakened by missing summary descriptive statistics in two studies, and four of the five publications either inadequately conducted or under-reported appropriate statistical analysis. There is some evidence that indigenous caregivers experience caregiver burden in areas of role conflict, negative emotions about the situation, concern about their capacity to provide care and guilt about not doing enough. Only one intervention study was found and several methodological concerns warrant caution in interpreting the reported treatment effects of significant, but small, improvements in stress, depression, bodily pain vitality and general health.

Discussion

The aim of this systematic literature review was to investigate indigenous caregivers' functioning and examine the evidence regarding interventions for this caregiver group. A secondary aim was to provide a detailed critique of the quantitative literature to help inform future research with indigenous caregivers. Recent grey literature (Eagar et al., 2007; Taylor, 2013) suggested that there would be a dearth of academic literature in this area. This was borne out by the current finding of only three studies examining some aspect of indigenous caregiver functioning and one randomised control trial for an intervention to alleviate indigenous caregiver stress.

Three of the studies contained numerous methodological weaknesses that limited the reliability and usefulness of their findings (Caqueo-Urizar, Gutierrez-

Maldonado, Ferrer-Garcia, & Darrigrande-Molina, 2012; Caqueo-Urizar, Gutierrez-Maldonado, Ferrer-Garcia, & Miranda-Castillo, 2012; Jervis et al., 2010; Korn et al., 2009). Despite the availability of stress and coping models that incorporate race/culture into explanations of caregiver functioning (e.g., Hilgeman et al., 2009; Knight, Silverstein, McCallum, & Fox, 2000; Pinquart & Sörensen, 2005) there was a marked absence of theoretical frameworks to help guide research questions and specific hypotheses. The studies used standardised assessment tools, but only one study (John et al., 2001) reported making specific cultural adaptations, and then tested to explore the conceptualisation of caregiver burden amongst an indigenous population. Limitations in sampling were due either to a lack of clear reporting of how the sample was selected (Caqueo-Urizar, Gutierrez-Maldonado, Ferrer-Garcia, & Darrigrande-Molina, 2012; Caqueo-Urizar, Gutierrez-Maldonado, Ferrer-Garcia, & Miranda-Castillo, 2012), or an insufficient exploration of potential bias arising from differences between respondents and non-respondents at different phases of the sample selection (Jervis et al., 2010; Korn et al., 2009). While most studies provided a range of socio-demographic data for the sample, the possible influence of these factors upon the variables of interest (e.g., caregiver burden, coping and reward) were not fully explored. Summary descriptive statistics were missing in two studies (Jervis et al., 2010; John et al., 2001); while a third study lacked a coherent account and justification for which inferential statistics were employed (Caqueo-Urizar, Gutierrez-Maldonado, Ferrer-Garcia, & Darrigrande-Molina, 2012; Caqueo-Urizar, Gutierrez-Maldonado, Ferrer-Garcia, & Miranda-Castillo, 2012). The sole intervention study located through this review (Korn et al., 2009) was at risk of an inflated Type I error rate due to inadequate statistical controls. The limited scope and

poor quality of the evidence base in this area has implications for future research, clinical practice and public policy.

While there are some qualitative findings that indicate the presence of psychological distress within the indigenous caregiving experience, the conceptualisation and prevalence of this distress requires much more investigation. Future studies need to include samples that are representative and of sufficient size. In addition, studies need to conduct adequate investigation into the potential sources of bias throughout the recruitment and selection of the sample, and ensure this is clearly reported. Despite the use of standardised measures in the studies included in this review, the appropriate use of assessment tools with indigenous samples can also be improved. More work is needed to test the cultural validity of assessment tools, as well as further exploration of the conceptualisation of key constructs, such as caregiver burden, within indigenous populations, building on the work of John et al. (2001). In addition, more sophisticated statistical analyses, including multivariate analyses and structural equation modelling, are needed to explicate the key factors and their relative contributions to caregiver distress and satisfaction. Future RCTs and non-randomised evaluations will benefit from use of research guidelines such as CONSORT (Moher et al., 2010) and TREND (Des Jarlais et al., 2004) to ensure methodological rigour and clear reporting of scientific standards. While there is already a growing consensus regarding the need for clear research and reporting standards (Kelley et al., 2003; NCDDR, 2005), what remains contentious is how this applies to cultural groups with a historical antagonism toward anglocentric agendas and methods (Rickwood, Dudgeon, & Gridley, 2010; Tuhiwai Smith, 1999).

Research is a cultural act; a meaning-making process that both reflects and defines a society's epistemological frontier (Tuhiwai Smith, 1999). In Australia, as in

other colonised-settler countries, psychological research has played an important part in relations between indigenous and non-indigenous populations (Rickwood et al., 2010; Tuhiwai Smith, 1999). For example, early forms of cognitive testing in Australia were predicated on the assumption that Indigenous Australians represented a less evolved human race, and deviations from average scores attained by non-Indigenous people were taken as confirmation of this racial inferiority (Rickwood et al., 2010). Though such overt racist agendas may no longer be pursued through scientific processes, it has been argued by theorists across several disciplines including, education, epidemiology and cross-cultural studies, that many contemporary research practices continue to replicate and perpetuate the colonising process (Tuhiwai Smith, 1999; Barnhardt & Kawagley, 2005; Wright, 2012).

However, some attempts to avoid research practices that disadvantage, ignore or violate indigenous values and worldviews may have other problems, including a failure to adhere to the standards of high quality research. This category can include surveys of indigenous people's unmet needs (e.g., Hepburn, 2005), evaluations of community-driven programs and models (e.g., Carroll et al., 2010; LoGiudice et al., 2012) and, literature reviews that draw on unscientific and unrepresentative information sources to make recommendations for interventions and policy (e.g., Taylor, 2013). Non-adherence to scientific methods is often implicitly justified in these studies, partly by a strong desire to privilege indigenous people's interests and voices over those of the (often non-indigenous or external) researcher (e.g., Hepburn, 2005). However, it also disregards the strong rationale for developing an empirical evidence base: the need to establish cause-and-effect relationships between interventions and recovery. Increasingly, health researchers are calling for improvements in standards of health research amongst indigenous people (Gone &

Alcantara, 2007; Sanson-Fisher, Campbell, Perkins, Blunden, & B.B., 2006; Stewart, Sanson-Fisher, Eades, & Mealing, 2010).

The nature of the research in this field to date is consistent with the prescience phase of scientific knowledge (Kuhn, 2012; Popper, 1973). Indicative of this phase is the proliferation of qualitative and speculative studies that aid in the conceptualisation of key phenomena and relationships (Kuhn, 2012). In addition, research among the majority culture population tends to precede studies that focus on minority groups. In Australia, the primary focus on caregivers in general is only about three decades old (Eagar et al., 2007), so predictably the state of the field for indigenous caregivers is behind. A report of NHMRC funding from 2000/01 to 2012/13 indicates that only one study with a specific focus on Indigenous Australian caregivers was awarded funding during this period (National Health and Medical Research Council, 2012). In fact, despite the steady increase in expenditure on indigenous health research over the last 13 years, approximately only 10% of the indigenous health projects funded from 2000/01 to 2012/13 had a psychosocial focus. Further, given that it is well-established that Indigenous Australians have a holistic view of health and wellbeing, incorporating physical, mental, social, cultural, spiritual, and community (Purdie, Dudgeon, & Walker, 2010) there may be incongruence between what is being researched and how that research translates to meaningful outcomes for the health and well-being of indigenous people (Tsey et al., 2007).

The biggest clinical implication arising from the current findings is a lack of knowledge about the degree and causes of indigenous caregiver distress and what interventions are effective for alleviation of this distress. Although the small amount of qualitative work in this area indicates that some indigenous caregivers do

experience psychological distress, this distress remains largely unspecified both in nature and relative intensity. In the mainstream, non-indigenous caregiver literature, depression and burden are key psychological variables of interest (Pinquart & Sörensen, 2005). The only study found in this review, that examined caregiver burden in an indigenous sample suggested that indigenous caregivers may experience caregiver burden in ways that both converge and differ from other cultural groups (John et al., 2001). In contrast to typical Western notions of nuclear, and even extended, family, indigenous individuals are often socialised to view many more people as belonging to their family network, resulting in numerous caregiving responsibilities, but also, ideally, multiple caregivers for any one care recipient (McGrath, 2008). Another belief that appears common among indigenous cultures is the notion of reciprocity: that those who cared for the young, deserve to be cared for in their old age (Hennessy & John, 1996; Smith et al., 2011). Furthermore, elders in particular tend to be perceived as culturally valuable because they act as repositories of cultural knowledge, language and family history (Smith et al., 2011). These beliefs may intersect and function to make caring for the ill, infirm and vulnerable members of a community congruent with indigenous caregivers' sense of self and value. This may minimise the caregiver stress that arises from role conflict, whereby caregivers experience distress because of restrictions on their ability to participate in other social, economic and relationship activities. Yet, there is some suggestion that role conflict is present among indigenous caregivers, when caregiving tasks limit their involvement in activities outside the home (Corbett et al., 2006; Dyall et al., 2008). Another form of role conflict reported among Native American samples was the perception that caregiving duties were being inadequately performed because of the pressures of other responsibilities such as formal employment (Crosato et al.,

2007; Hennessy & John, 1996). Indigenous caregivers may therefore be more susceptible to experiencing guilt due to being unable to fulfil the caregiving responsibilities prescribed by cultural norms (John et al., 2001).

The social context of indigenous populations in general, and Indigenous Australians in particular, also gives rise to a number of unique stressors. Factors such as lack of culturally accessible support services, distance from services, premature mortality and morbidity, individual-, institutional- and cultural-racism, generally poor health and AOD issues constitute pervasive stressors for the majority of Indigenous Australians, contributing to a weakening of the kinship networks that can share the caregiving load (Emden et al., 2005). These stressors are likely to be compounded for those who do take on the caregiver role (Wright, 2012) and then face multiple and constant caregiving responsibilities and a lack of adequate resources including power and transport (Smith et al., 2011). These social determinants of caregiver health are also in need of strategic intervention at the level of public policy; however, the lack of evidence about what is driving indigenous caregiver stress remains a limiting factor in the development of effective policies.

The current review involved a primary assessor, with counter-checking from a second researcher, in the search, selection and data extraction of studies. To strengthen the methodology, future reviews should use independent data extraction by two reviewers as recommended by the PRISMA guidelines (Liberati et al., 2009). Furthermore, due to the nature of the studies included in the review, another limitation is that the conclusions may only generalise to a very small group of indigenous caregivers (i.e., groups in North and South America). Notably, no studies were included in the review that focused on Aboriginal and Torres Strait Islander people. When more studies are conducted with a greater diversity of indigenous

peoples, it will be possible to look at the factors that contribute to differences in the indigenous caregiving experience.

With increases in the aging population and chronic diseases apparent worldwide, the role of informal caregivers is likely to remain an important source of support for elderly, ill and disabled people. This review has revealed that there is extremely limited evidence about the functioning of indigenous caregivers and what interventions are effective in alleviating their distress. The few quantitative studies that have been done in this area have lacked methodological rigour, thus undermining the reliability and credibility of their findings. The lack of knowledge about indigenous caregiver functioning and how to support it is concerning, particularly given the substantial disadvantages already present amongst indigenous peoples. Without advancements in the field there is a risk that indigenous caregivers may not receive adequate interventions and that policies will be ill-informed. The findings from this review suggest that the main priority to advance the field is for future research to adhere to best practice research standards.

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Appendix A

Summary of studies excluded from the review

Appendix A: Summary of studies excluded from the review

	Study ID	Publication type	Study design	Country	Reason for exclusion
1	Cotter, Anderson, and Smith (2007)	Chapter in edited book	Commentary drawing on data from ABS and AIHW	Australia	Not a study. Small section on carers makes general comments drawn from the literature with no direct references.
2	Aboriginal Disability Network (2007)	Unpublished report	Qualitative –community consultation	Australia	Focus on care recipients (ATSI people with a disability). Brief mention made regarding carers.
3	Aspin, Brown, Jowsey, Yen, and Leeder (2012)	Journal article	Qualitative	Australia	Focus on care recipients (ATSI people with chronic illness).
4	Bentelspacher, Chitran, and Rahman (1994)	Journal article	Mixed methods – qual & quant	Singapore	Not indigenous.
5	Blume (2008)	Abstract	Quantitative – SEM & intervention?	United States	Abstract only – insufficient information to include. Author contacted for full-text publication information. Response: study not published.
6	Boss, Kaplan, and Gordon (1994)	Abstract	Qualitative	United States	Abstract only – insufficient information to include. Author contacted for full-text publication information. Response: directed to book chapter (see next two references).

Appendix A: Summary of studies excluded from the review

7	Boss, Kaplan, and Gordon (1995)	Article	Qualitative	United States	Excluded as not peer-reviewed: published in the local journal.
8	Boss (1999)	Book	Commentary/clinical opinion	United States	Not a study; briefly and anecdotally refers to data collected in previous reference.
9	Brodaty and Cumming (2010)	Commentary	Commentary	Australia	Commentary about dementia services in Australia. Brief mention of the importance of family caregivers and the gaps in knowledge & service for indigenous people with dementia and their carers.
10	Bruce, Paley, Underwood, Roberts, and Steed (2002)	Journal article	Qualitative	Australia	Indigenous status not reported.
11	Butterworth, Pymont, Rodgers, Windsor, and Anstey (2010)	Journal article	Quantitative	Australia	Indigenous status not reported.
12	Cass, Smith, Hill, Blaxland, and Hamilton (2009)	Social Policy Paper	Quantitative –descriptive & Qualitative-focus groups	Australia	Quantitative: describes numbers of ATSI young carers. Qual: one brief mention of a respite camp for ATSI young carers. Repeated calls for the need for more research into this group.

Appendix A: Summary of studies excluded from the review

13	Cass, Yeandle, and Policy (2009)	Conference paper	Commentary/analysis	Australia & United Kingdom	Does not provide data on outcomes for carers. Focus is on policy.
14	Castleden, Crooks, Hanlon, and Schuurman (2010)	Journal article	Qualitative	Canada	Does not provide data on outcomes for carers.
15	Creswell (2012)	Submission for government green paper	Commentary	Australia	Nearly all references contained in this document are part of the current review.
16	de Crespigny, Kowanko, Murray, Emden, and Wilson (2005)	Journal article	Overview of research project (lit review, qualitative research & survey data)	Australia	Small section on carers in this article does not contain sufficient detail to include in the review. Overview makes reference to details of project in various publications. Those deemed potentially eligible have been located and added to search.
17	Edwards, Higgins, Gray, Zmijewski, and Kingston (2008)	Research report	Quantitative	Australia	Carers outcomes not reported according to Indigenous status
18	Forbes and Edge (2009)	Journal article/policy analysis	Commentary	Canada	No data regarding carer outcomes.
19	Frerichs, Schumacher, Watanabe-Galloway, &	Journal article/program development	Descriptive program development	United States	No carer outcomes.

Appendix A: Summary of studies excluded from the review

	Duran (2012)				
20	Frizzell & Chamberlain (2006)	Report	Commentary/policy and funding analysis	Australia	No carer outcomes.
21	Garrett et al. (2010)	Journal article	Quantitative- secondary data analysis	United States	No carer outcomes.
22	Goins et al. (2011)	Journal article	Quantitative	United States	Examines links between culture and caregiving among Native Americans; but does not report any outcomes.
23	Carers Australia	Book/intervention resource	n/a	Australia	Not a study. It is actually an intervention/resource for ATSI carers. Will make detailed description of it; need to locate an evaluation of it.
24	The Echidna Group (2009)	Feasibility report	Qualitative	Australia	No outcomes for carers: focus on the issues associated with model of respite care and recommendations for an alternative model
25	Habjan, Prince, & Kelley (2012)	Journal article/study	Qualitative	US	No outcomes for carers specified.
26	Hancock, Jarvis, & L'Veena, (2006)	Journal article/study	Qualitative	Australia	Not indigenous. Only 2 out of 62 carer participants were of ATSI background. As it is a qualitative analysis, this small proportion means that the overall themes may not be reflective of the ATSI perspective/experience. The author

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					acknowledges that the program was not inclusive of ATSI carers.
27	Hancock, Jarvis, & L'Veena, (2007)	Journal article/study	Mixed methods	Australia	Not indigenous. See previous reference.
28	Harris et al., (2004)	Journal article/study	Qualitative	Australia	No indigenous participants identified.
29	Henderson, (2009)	Abstract	Case study	United States	Abstract only. Author contacted for additional full-text publication information. Response: no response.
30	Hill, Smyth, Thomson & Cass (2009)	Report	Analysis of census data and the Survey of Disability Aging and carers (SDAC) & qualitative	Australia	Some background context for indigenous young carers (gender, age, education, employment) but no outcomes.
31	Hill, Thomson & Cass (2011)	Report	Analysis of survey data	Australia	Focus on economic outcomes.
32	Hill, Thomson & Cass (2010)	Presentation	Theoretical discourse	Australia	A generic model for conceptualising care; authors note it would need further development to apply to ATSI population.
33	Jenkins & Seith, (2004)	Report	Background policy paper	Australia	Not a study; draws on evidence that I have as primary sources.
34	Jeon, Essue, Jan, Wells, & Whitworth, (2009)	Journal article/study	Qualitative	Australia	No carer outcomes.

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35	Jervis & Manson, (2002)	Journal article	Commentary/ discursive paper	United States	Not a study.
36	Jones, Lee, & Zhang (2011)	Journal article/study	Quantitative	United States	Scale development for values toward caregiving among different cultural groups rather than measured outcomes.
37	Jorm, Walter, Lujic, Byles, & Kendig (2010)	Journal article/study	Quantitative	Australia	Analysis of linked datasets; does not distinguish data for care recipients and providers.
38	Jowsey, Yen, Wells & Leeder (2011)	Journal article/study	Qualitative	Australia	Brief mention of carers but not specifically indigenous.
39	Kane & Houston-Vega (2004)	Journal article/commentary	Commentary	United States	Uses data from sources that I have. Compares different cultural groups including Native Americans.
40	Kelly et al., (2009)	Journal article/commentary	Qualitative	United States	No outcomes for caregivers, focus is on care recipient.
41	Kowanko, De Crespigny, & Murray (2003)	Report/study	Mixed methods- lit review, qualitative interviews, analysis if hospital separation stats.	Australia	No outcomes for carers.
42	Lanting, Crossley, Morgan, & Cammer (2011)	Journal article/study	Qualitative	Canada	No specific outcomes for carers.
43	LoGiudice et al. (2012)	Journal article/study	Quantitative – basic program evaluation	Australia	Evaluation of a model of care but no carer specific outcomes reported
44	Maddocks &	Journal	Commentary	Australia	Not a study. A brief commentary

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	Rayner (2003)	article/commentary			about palliative care.
45	Marr, Neale, Wolfe, & Kitzes, (2012)	Journal article/study	Quantitative	United States	No outcomes for carers reported.
46	Martin & Paki, (2012)	Journal article/case study	Commentary/case study	New Zealand	No outcomes for carers.
47	McCallion, Janicki, & Grant-Griffin (1997)	Journal article/study	Qualitative	United States	No outcomes for carers reported. Tries to locate relevant issues across various cultures that influence service use etc.
48	McGrath (2007)	Journal article/study	Qualitative	Australia	No carer outcomes; focus on care recipient's needs/preferences for dying.
49	McGuire, Okoro, Goins, & Anderson (2008)	Journal article/for the patient	Commentary	United States	Not a research study; commentary describing some research in lay terms.
50	McLeod, Nolan, & Dewing (2012)	Journal article/program description	Descriptive commentary	Australia	Not a research study
51	McMahon & Hardy	Report	Mixed methods- lit review, policy analysis, qualitative focus groups.	Australia	No outcomes for carers but in depth analysis of problems associated with people identifying as carers. Small reference to particular difficulties for ATSI population in this regard.
52	Monahan & Twining (2006)	Practice guidelines	Practice guidelines: descriptive	Australia	Detailed guidelines for working with indigenous carers: no evaluation of this approach.

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53	Nagel, Robinson, Condon, & Trauer (2009)	Journal article/study	Quantitative - RCT	Australia	No carer outcomes.
54	Carers NSW (2010)	Resource manual	Resource manual	Australia	Non-academic resource providing background and guidelines for providing support to Indigenous carers. No evaluation or reference to evaluation.
55	Hancock & Jarvis (2005)	Journal article/study	Quantitative –descriptive survey no inferential stats	Australia	Does not include outcomes for carers generally, or ATSI carers specifically, despite identifying this as an aim of the program in the introduction. Provides good history of development of carer focus in policy and legislation.
56	Palliative Care Australia (2004)	Report	Literature review and qualitative data (submissions from carers and service providers)	Australia	No clearly identified indigenous carer outcomes; except for submissions from service providers regarding the needs of this 'special' group.
57	Parrack & Joseph (2007)	Journal article/commentary	Commentary/discursive review	Canada	Not a research study
58	Pearce (2000)	Journal article/commentary	Opinion piece	Australia	Not a research study. An opinion piece from a male ATSI carer.
59	Pelling et al. (2006)	Study	Quantitative survey	Australia	No indigenous specific outcomes.

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60	Pollitt 1997)	Journal article/commentary	Commentary	Australia	No carer outcomes; care recipient focus, despite mentioning carers in abstract, introduction and conclusion.
61	Poroch, Manion, & Manion (2012)	Journal article/commentary	Commentary/program description	Australia	Does not detail carer outcomes, and is not a research study as such. More of a descriptive commentary on a program adaptation. Provides a lot of detail on some aspects of Aboriginal cultures.
62	Ramanathan & Dunn (1998)	Journal article/study	Qualitative	Australia	No carer outcomes. Research report is quite informal.
63	Ramsay, Samsa, Owen, Stevermuer, & Eagar (2007)	Report	Mixed methods? Assessment tool development	Australia	No carer outcomes included. Describes the development of a carer needs assessment tool. Does include consultations with relevant stakeholders on adapting the tool to ATSI populations.
64	Rehman, Reading, & Unruh (2009)	Journal article/study	Qualitative	Canada	Not indigenous. Mixed sample of caregivers, including aboriginal women, but does not clearly identify their data except for two quotes at the start. Part of a larger study.
65	Scharlach et al. (2006)	Journal article/study	Qualitative –focus groups	United States	Not indigenous. Excluded because although it includes a focus group of Native American caregivers, the report synthesizes findings across 8

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					cultural groups and therefore results are not specific to Native Americans but rather specific to minority cultures compared to majority culture. Also, not a real focus on carer outcomes (small mention of experience of caregiving) so much as reasons for caregiving, barriers to service.
66	Schulz (1997)	Thesis	Qualitative	Canada	Excluded; no clearly articulated carer outcomes. Carer experiences are entangled with parental experiences.
67	Smith (1996)	Journal article/review	Critical review	Cross-cultural; no countries specified	No carer outcomes specifically discussed; not a research study.
68	Smith, Grundy, & Nelson (2010)	Journal article	Case study	Australia	No carer specific outcomes, however highlights that the conceptual distinction between formal and informal caregiving may not be appropriate in indigenous settings. Details the development of a model for working with older care recipients in which family are the workers. Does not actually talk about impact on carers, informal or otherwise so cannot be included.

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69	Smyer & Clark, (2011)	Journal article/commentary	Review/commentary	United States	Commentary, no original data on carer outcomes.
70	Smyth, Blaxland, & Cass (2011)	Journal article/study	Qualitative	Australia	Brief mention of Indigenous population but no carer outcomes.
71	St. Pierre-Hansen, Kelly, Linkewich, Cromarty, & Walker (2010)	Journal article	Descriptive program development	United States	No carer outcomes.
72	Stewart, Lohoar, & Higgins (2011)	Government resource sheet	Review	Australia	Not a research study; no carer outcomes.
73	Stopher & D'Antoine (2008)	Report?	Report/review	Australia	Not a research study; does briefly mention some caregiver experience drawing on data from an unpublished report.
74	Sullivan, Blignault, Aunt Shirley, & Lisa Jackson (2007)	Journal article	Program description	Australia	Not a study.
75	Taylor, Lindeman, Stothers, Piper, & Kuipers (2012)	Journal article/resource evaluation	Qualitative resource evaluation	Australia	No carer outcomes.
76	ARTD	Report	Mixed methods	Australia	No carer outcomes.

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	Consultancy Team et al.		intervention evaluation		
77	Tomita et al. (2010)	Journal article/study	Quantitative	Cross-cultural: United States, Taiwan, & India	No indigenous-specific data reported.
78	Tripp (1993)	Journal article	Personal story/opinion	Australia	Not a research study
79	Disability Policy Research Working Group (2011)	Green paper?	Policy research paper	Australia	No carer outcomes
80	Turner & Findlay (2012)	Journal article	Quantitative	Canada	No indigenous specific data.
81	Vlahos (2005)	Thesis	Qualitative	Canada	No carer outcomes.
82	Warmington, Haynes, Chong, & Schneider (2005)	Conference paper	Program description	Australia	Not a study-no evaluation.
83	Williams & Owen (2009)	Journal article/review	Published article of Eagar et al., 2007 review	Australia (and international)	Not a research study with original data.
84	Yap & Biddle (2012)	Report	Quantitative	Australia	No carer outcomes.
85	Holm & Ziguras (2003)	Journal article/program description	Program description & qualitative evaluation (satisfaction)	Australia	No indigenous outcomes reported despite reference to the model being aimed at meeting 'Koori' needs.
86	Orcher (1995)	Report	Qualitative/survey - unclear	Australia	No carer outcomes reported; focus on service gaps and needs.

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87	Hobbs (1989)	Report	Mixed methods: literature review, qualitative, survey	Australia	No carer outcomes; focus on care recipient.
88	Henry & Smith (2002)	Report	Case study	Australia	No carer outcomes; focus is on child-care and mobility issues.
89	Valle (1988)	Journal article	Intervention description/commentary	United States	Not a research study. Does not include any actual data on caregiver outcomes or evaluation of the proposed model/process for outreach. Also focuses on Black Americans as a proxy for Native Americans.
90	Carers Australia	Report	Unknown	Australia	Came up in search results but actual document does not seem to exist.
91	Winterton & Warburton (2011)	Journal article/review	Systematic review	Australia	A review paper and may be the journal publication connected to the Eagar report already cited in the introduction.
92	Fuller-Thomson & Minkler (2005)	Journal article/study	Quantitative	United States	No carer outcomes for the carers of interest; focus is on grandparents.
93	Kimberley Aged and Community Services (2008)	Report	Unknown	Australia	Not published in a peer-reviewed journal and full-text cannot be located/obtained
94	A. Williams, Indigen, & Us (2009)	Report	Unknown	Australia	Not published in a peer-reviewed journal and full-text cannot be located/obtained
95	Prokop, Haug,	Book chapter	Commentary, review	United States	Not a research study; commentary

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	Hogan, McCarthy, & MacDonald (2003)				of the issues
96	Haley & Harrigan (2004)	Journal article/study	Qualitative – ethnographic study	Pacific Islands	Does not meet definition of indigenous for the purposes of this review.
97	Burns (2012)	Report	Survey & Qualitative	Australia	Carers' issues embedded in broader focus on aged care needs in Sydney. Non peer-reviewed publication from FACSIA. Raises psychosocial issues: dependence on older person's pension and no negative experiences associated with caring.
98	Bray (2013)	Report	Quantitative, longitudinal	Australia	Not peer reviewed. Provides info about the likelihood of being on income support post-care period for young indigenous carers.
99	Carroll et al. (2010)	Report	Qualitative (unmet needs study) and quantitative (descriptive stats for evaluation of model of care.	Australia	Excluded as the data on which model is based is included in the smith ref which is in a journal article. The model of care derived from that data is only reported in this non peer-reviewed report and provides insufficient data for evaluation of carer outcomes.
100	Department of	Report	Qualitative –focus groups	Australia	Not peer-reviewed.

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	Family and Community Services (2012)				
101	Edwards, Gray, & Hunter (2011)	Journal article/study	Quantitative	Australia	No psychological outcomes reported.
102	Hepburn (2005)		Qualitative-focus groups	Australia	Not peer-reviewed.
103	Jowsey, Yen, Aspin, Ward & Team (2011)		Qualitative - interviews	Australia	Not peer-reviewed.
104	McGrath et al. (2006)	Journal article/study	Qualitative	Australia	Indirect findings about carers' outcomes; cannot distinguish between carer, patient and worker report.
105	Shanley, Roddy, Cruysmans, & Eisenberg (2004)	Journal article/study	Qualitative intervention evaluation	Australia	Excluded as insufficient data provided to allow rigorous evaluation of the program; however it is noted that the support group for Aboriginal caregivers failed to attract participants possibly due to a lack of cultural appropriateness.
106	Van Ast (2006)	Report	Qualitative: Intervention evaluation	Australia	Excluded as insufficient data provided in the Methods and Results regarding the one indigenous participant.
107	Wright (2012)	Book chapter	Qualitative	Australia	Qualitative. Not peer-reviewed.
108	Kenney & Malone (2007)		Qualitative	Australia	Not peer-reviewed.

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109	Kurnoth & Hall (1993)	Journal article	Qualitative – case study	Australia	Provides insufficient data about the carers' experiences
110	Braun, Takamura, Forman, & Sasaki (1995)	Journal article	Intervention development & quantitative evaluation	United States	Excluded because outcome from the program are awareness of dementia symptoms. While this can impact on caregiver functioning no measures of caregiver functioning were included.
111	Buchignani & Armstrong-Esther (1999)		Survey and qualitative	Canada	Seems like hybrid between study and commentary. Does not focus on caregiver outcomes or point of view.
112	Conway, Boeckel, Shuster, & Wages (2010)	Journal article	Quantitative	United States	This study was only considered as it examined whether grandparents experienced caregiver burden for children with disabilites; however the data did not separate this relationship out across racial groups- so exclude.
113	DeCourtney, Branch, & Morgan (2010)		Qualitative	Canada	Excluded because small focus on caregivers is not about psychosocial experiences and outcomes, but the effect of bereavement on the caregiving process/role.
114	Giunta, Chow, Scharlach, & Dal Santo	Journal article	Quantitative	United States	Did not report sufficient data for the NI/AN category.

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	(2004)				
115	McGuire, Okoro, Goins, & Anderson (2008)		Quantitative	United States	No psychological outcomes reported; only likelihood to provide care.
116	Ludtke, McDonald, & Vallestad (2003)		Quantitative	United States	Not peer-reviewed.
117	Gahagan, Rehman, Loppie, Side, & MacLellan (2004)	Report	Qualitative	Canada	The sample is mixed and the data are not reported by cultural group. Therefore excluded. Also the definition of caregiving is broader than that used in this study; includes normative caregiving practices for everyone not just vulnerable people.
118	Schulz & Farrell (1998)	Journal article	Qualitative	Canada	Focuses on difficulties around caring without explicitly examining the psychological effects of this, therefore excluded.
119	Anngela-Cole & Busch (2011)	Journal article	Qualitative	United States	Qualitative
120	Corbett, Francis, & Chapman (2006)	Journal article	Qualitative	New Zealand	Qualitative
121	Crosato, Ward-Griffin, & Leipert (2007)	Journal article	Qualitative	Canada	Qualitative
122	Dyall, Feigin, &	Journal article	Qualitative	New Zealand	Qualitative

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	Brown (2008)				
123	Emden, Kowanko, de Crespigny, & Murray (2005)	Journal article	Qualitative	Australia	Qualitative
124	Evans-Campbell, Fredriksen-Goldsen, Walters, & Stately (2005)	Journal article	Qualitative	United States	Qualitative
125	Hennessy & John (1995)	Journal article	Qualitative	United States	Qualitative
126	Hennessy & John (1996)	Journal article	Qualitative	United States	Qualitative
127	Hennessy, John, & Anderson (1999)	Journal article	Qualitative	United States	Qualitative
128	McGrath (2008)	Journal article	Qualitative	Australia	Qualitative
129	Smith et al. (2011)	Journal article	Qualitative	Australia	Qualitative
130	Strong (1984)	Journal article	Qualitative	United States	Qualitative
131	Ward, Jowsey, Haora, Aspin, & Yen (2011)	Journal article	Qualitative		Qualitative

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Appendix C

Summaries of research quality against best-practice guidelines for each included study

Appendix C: Summaries of research quality for included studies

Study ID: Korn, Logsdon, Plissar, Gomez-Beloz, Waters, & Ryser (2009)

Section/Topic	Item No	Checklist item	Reported on page No	Comments
Title and abstract				
	1a	Identification as a randomised trial in the title	1 (368)	
	1b	Structured summary of trial design, methods, results, and conclusions (for specific guidance see CONSORT for abstracts)	1 (368)	
Introduction				
Background and objectives	2a	Scientific background and explanation of rationale	1-3 (368-370)	
	2b	Specific objectives or hypotheses	3 (370)	
Methods				
Trial design	3a	Description of trial design (such as parallel, factorial) including allocation ratio	Not reported	
	3b	Important changes to methods after trial commencement (such as eligibility criteria), with reasons	n/a	
Participants	4a	Eligibility criteria for participants	3 (370)	
	4b	Settings and locations where the data were collected	Not reported	
Interventions	5	The interventions for each group with sufficient details to allow replication, including how and when they were actually administered	4-5 (371-372)	Frequency of sessions not reported
Outcomes	6a	Completely defined pre-specified primary and secondary outcome	5-6 (372-373)	

Appendix C: Summaries of research quality for included studies

		measures, including how and when they were assessed		
	6b	Any changes to trial outcomes after the trial commenced, with reasons	n/a	
Sample size	7a	How sample size was determined	Not reported	
	7b	When applicable, explanation of any interim analyses and stopping guidelines	n/a	
Randomisation:				
Sequence generation	8a	Method used to generate the random allocation sequence	Not reported	
	8b	Type of randomisation; details of any restriction (such as blocking and block size)	5 (372)	Stratified randomisation using a cut-off on the PSS scale to ensure balanced numbers of caregivers with low and high perceived stress in each condition.
Allocation concealment mechanism	9	Mechanism used to implement the random allocation sequence (such as sequentially numbered containers), describing any steps taken to conceal the sequence until interventions were assigned	Not reported	
Implementation	10	Who generated the random allocation sequence, who enrolled participants, and who assigned participants to interventions	5 (372)	Statistician randomised caregivers into conditions.
Blinding	11a	If done, who was blinded after assignment to interventions (for example, participants, care providers, those assessing outcomes); how	5 (372)	Assessors were blinded to participants' conditions; however, no report of participants

Appendix C: Summaries of research quality for included studies

				being blinded as to whether they were in the treatment or control group
	11b	If relevant, description of the similarity of interventions	5 (372)	Control respite condition excluded therapies similar to the experimental condition
Statistical methods	12a	Statistical methods used to compare groups for primary and secondary outcomes	6 (373)	Multiple t-tests. No umbrella multivariate test = possible inflated type I error. No tests for multi-collinearity of outcome measures, despite reporting multiple scores from the same instrument (SF-36).
	12b	Methods for additional analyses, such as subgroup analyses and adjusted analyses	6 (373)	Regression model to control for confounding variables
Results				
Participant flow (a diagram is strongly recommended)	13a	For each group, the numbers of participants who were randomly assigned, received intended treatment, and were analysed for the primary outcome	3 (370) & 6 (373)	Flowchart included.

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	13b	For each group, losses and exclusions after randomisation, together with reasons	3 (370)	Losses reported without reasons.
Recruitment	14a	Dates defining the periods of recruitment and follow-up	Not reported	
	14b	Why the trial ended or was stopped	n/a	
Baseline data	15	A table showing baseline demographic and clinical characteristics for each group	7 (374)	Apparently large difference in mean age of the groups is not tested for significance.
Numbers analysed	16	For each group, number of participants (denominator) included in each analysis and whether the analysis was by original assigned groups	6 (373)	
Outcomes and estimation	17a	For each primary and secondary outcome, results for each group, and the estimated effect size and its precision (such as 95% confidence interval)	7-8 (374-375)	No effect sizes or confidence intervals not reported
	17b	For binary outcomes, presentation of both absolute and relative effect sizes is recommended	n/a	
Ancillary analyses	18	Results of any other analyses performed, including subgroup analyses and adjusted analyses, distinguishing pre-specified from exploratory	7 (374)	Mulitvariate analyses of potential confounding variables fails to include age as a covariate, despite seemingly large difference in the groups' mean age.
Harms	19	All important harms or unintended effects in each group (for specific guidance see CONSORT for harms)	7 (374)	

Appendix C: Summaries of research quality for included studies

Discussion				Authors note the need for follow-up assessment and the need for a control condition that has similar level of therapeutic intensity as the experimental condition.
Limitations	20	Trial limitations, addressing sources of potential bias, imprecision, and, if relevant, multiplicity of analyses	9 (376)	
Generalisability	21	Generalisability (external validity, applicability) of the trial findings	8 (375)	
Interpretation	22	Interpretation consistent with results, balancing benefits and harms, and considering other relevant evidence	8-9 (375-376)	
Other information				
Registration	23	Registration number and name of trial registry	9 (376)	
Protocol	24	Where the full trial protocol can be accessed, if available	Not reported	
Funding	25	Sources of funding and other support (such as supply of drugs), role of funders	9 (376)	
Review Conclusions	The authors report that polarity therapy was found to significantly reduce perceived stress, depression and pain compared to Enhanced Respite; however there are several substantial limitations as detailed above which suggest that the results may be at risk of Type I error.			

Appendix C: Summaries of research quality for included studies

Study ID	John, Hagan Hennessy, Dyeson, & Garrett (2001)
Explain the purpose or aim of the research, with the explicit identification of the research question	To determine whether caregiving burden is multidimensional in the NA population. P. 3 (212)
Explain why the research was necessary and place the study in context, drawing upon previous work in relevant fields (lit review)	General aging population and reliance on family caregiving. Lack of knowledge about NA experience of caregiving and how stresses are handled in this population. Most research in this area has been small, qualitative studies. Previous research suggests that there are stressors and burden associated with caregiving but there is evidence that this is interpreted as due to difficulties in fulfilling the caregiving role well rather than having to do it. Mixed findings about the degree of passivity-control NA caregivers experience in the role and how this approach links to experience of burden. P. 1-3 (210-212)
Described in detail how the research was done:	p. 3-4 (212-213)
a) State the chosen research method and justify why this was chosen	Lack of evidence around the conceptualisation of burden in this population, so a quantitative analysis of different dimensions of burden was conducted.
b) Describe the research tool	Caregiver burden scale adapted from Zarit Burden Inventory (adaptations are described). Additional measures: ADL & IADL, Cognitive Status scale
c) Describe how the sample was selected and how data were collected:	
i) How were potential subjects identified?	Participants were recruited by staff from local American Indian senior service according to eligibility criteria.
ii) How many and what type of attempts were made to contact participants?	A purposive but representative sample (due to small community and knowledge about everyone's circumstances).
iii) Who approached potential participants?	Participants were interviewed by an indigenous service provider. Interviews
iv) Where were they approached?	took place in caregivers' home or another
v) How was informed	

Appendix C: Summaries of research quality for included studies

consent obtained?	mutually acceptable location to assure privacy. Interviewers were trained by the researchers. Interview was read out. Consent procedures not reported.
vi) How many agreed to participate?	169 agreed to participate; non participant characteristics not reported.
vii) How did those who agreed differ from those who did not agree?	
viii) What was the response rate?	
Describe and justify the methods and tests used for data analysis	P 5 (214) Exploratory factor analytic methods were used to examine the dimensions underlying burden in this sample. Clear report of the details of the analysis and why it was used.
Present the results of the research: clear, concise and factual	P. 5-7 (214-216) Four factors found: role conflict (classic concept of burden), negative feelings (toward care recipient), caregiver efficacy and guilt.
Interpret and discuss the findings	p. 7-10 (216-219) In other studies, NA sample denied much burden; perhaps a artefact of the focus group methodology which would involve admitting burden in front of others when it is not culturally sanctioned. Explores how these dimensions of burden relate to NA culture and circumstance. Discusses how they differ from other findings of the dimensions of burden (mostly not a lot of work has been done in this area).
Present conclusions and recommendations.	Identifying specific types of burden experienced can allow for better targeting of interventions.
Review conclusions	Strong methodological rigour. Absence of quantitative results for this sample makes it difficult to compare with other groups.

Appendix C: Summaries of research quality for included studies

Study ID	Jervis, Boland, & Fickenscher (2010)
Explain the purpose or aim of the research, with the explicit identification of the research question	To examine caregiving among the American Indian population within its cultural context. P. 3 (357)
Explain why the research was necessary and place the study in context, drawing upon previous work in relevant fields (lit review)	Despite aging population, little is known about informal caregiving in the AI population. There is evidence that caregiving has negative and burdensome aspects among the general population and more recently has been demonstrated to have some positive aspects too. These experiences are believed to vary across racial/cultural groups but has not been much explored in at AI population. A couple of previous studies suggest that there are negative and positive aspects to caregiving among this group. P. 1-3 (355-357)
Described in detail how the research was done:	p. 3-6 (357-360)
a) State the chosen research method and justify why this was chosen	Mixed methods. Qualitative data is justified because researchers are seeking to understand how caregiving manifests and is experienced subjectively.
b) Describe the research tool	Quantitative measures collected through structured interview using standardised measures: Activities of Daily Living and Instrumental Activities of Daily Living, Zarit Burden Inventory and Positive Aspects of Caregiving Measure. Qualitative data was collected through semi-structured interview.
c) Describe how the sample was selected and how data were collected:	
i) How were potential subjects identified?	Participants were identified from senior nutrition sites (which excludes elders who were remote or uninterested). As part of a larger study of AI elders, researchers asked the 140 elders if they could contact a family member who assisted them; 53 agreed. No reported analysis of the difference between those care recipients and caregivers for whom permission was given and those for
ii) How many and what type of attempts were made to contact participants?	
iii) Who approached potential participants?	
iv) Where were they approached?	
v) How was informed	

Appendix C: Summaries of research quality for included studies

consent obtained? **vi) How many agreed to participate?** **vii) How did those who agreed differ from those who did not agree?** **viii) What was the response rate?**	whom it was not. Of those caregivers approached 16 of them did not identify as family caregivers and therefore did not meet eligibility criteria. Of the 20 caregivers to be interviewed one was dropped out of the analysis due to missing data. Those caregivers whose care recipients had low or discrepant scores on the MMSE and the Mattis Dementia Rating Scale were approached first. No differences were found in these care recipient scores for caregivers participating and those who did not.
Describe and justify the methods and tests used for data analysis	Quantitative: due to small sample size no inferential statistics were used on the quantitative data, except to compare the MMSE and MDRS scores of the care recipients whose caregivers did and did not participate. No summary statistics (means) given for the quantitative data. Qualitative: Data was recorded and transcribed. Codes were derived from the data and continued to emerge until saturation was reached. Text was then coded and subjected to thematic analysis. All data was accounted for. Researchers did not report critical reflection on their roles, bias or skills.
Present the results of the research: clear, concise and factual	p. 6-11 (360-365)Quantitative: Caregivers reported low levels of assistance with everyday tasks, low levels of burden and high levels of satisfaction; limited quantitative statistics given to support this interpretation by the authors. Qualitative: cultural context makes sense of these findings. Core cultural belief about respect for elders; as well as believe that this traditional value has suffered considerable erosion. Caregivers had negative views of nursing homes. Reciprocity both past and future focussed. Reasons for lack of burden: low level of assistance required, proximity to the care recipient, lack of competing interests,

Appendix C: Summaries of research quality for included studies

	multiple caregivers. They feel valued and appreciated in the caregiver role, pleasure from being with the elder, emotional closeness, wisdom and advice received, practical support (money) from elder.
Interpret and discuss the findings	p. 11- (365-) There was consistency across quantitative and qualitative data. Reasons for reported low levels of assistance may be due to wording and interpretation of question (participants may have not considered many of things they do as caregiving activities but just normal behaviours). Discussion of the multiple reasons that this group may experience low burden and high satisfaction. Limitations: purposive sample with one tribe so may not generalise.
Present conclusions and recommendations.	The finding about enjoying the elder's humour and fun may be worthy of further attention as it does not come up often in the literature. Overall, the findings of low burden and high satisfaction are surprising given the resource restrictions and remoteness of the location.
Review conclusions	This mixed methods study undermines the power of using mixed methods by having an insufficient sample size to conduct inferential analyses. Absence of summary quantitative statistics makes comparisons difficult. The lack of exploration of difference between caregivers who participates and those that did not, is a potential source of bias.

Appendix C: Summaries of research quality for included studies

Study ID	Caqueo-Urizar, Gutierrez-Maldonado, Ferrer-Garcia, & Darrigrande-Molina (2012a); Caqueo-Urizar, Gutierrez-Maldonado, Ferrer-Garcia, & Miranda-Castillo (2012b)
Explain the purpose or aim of the research, with the explicit identification of the research question	Assess the levels of burden and evaluate the coping strategies of Aymaran caregivers in comparison to non-Aymaran caregivers.
Explain why the research was necessary and place the study in context, drawing upon previous work in relevant fields (lit review)	Bulk of caregiving of people with schizophrenia among Chilean population occurs informally. Well-documented caregiver distress associated with this among other caregiver populations. Family caregivers in ethnic minorities possibly face double stigma due to the mental illness and lower social status. Although traditional Aymaran cosmology might be a protective factor, the increase in urban living may be eroding the protection that once existed.
Described in detail how the research was done:	
a) State the chosen research method and justify why this was chosen	Described as a case-control study – no justification
b) Describe the research tool	Zarit Burden Scale. References to validation in Spanish. Description of dimensions.
c) Describe how the sample was selected and how data were collected:	
i) How were potential subjects identified? **ii) How many and what type of attempts were made to contact participants?** **iii) Who approached potential participants?** **iv) Where were they approached?** **v) How was informed consent obtained?** **vi) How many agreed to participate?** **vii) How did those who agreed differ from those who did not agree?** **viii) What was the response**	The identification, selection and approach of participants not reported. No examination of differences between respondents and non-respondents. No response rate reported. No random sampling technique reported. Reported informed consent procedures.

Appendix C: Summaries of research quality for included studies

rate?	
Describe and justify the methods and tests used for data analysis	In the report on burden (2012a) no explanation or justification of data analysis; unclear whether single or multiple analyses were run (difficult to determine possible inflation of Type I error rate). In the report on coping (2012b) data analysis is described and justified.
Present the results of the research: clear, concise and factual	In the burden report some analysis of demographic differences between the groups. Despite educational differences being found this is not incorporated into the primary analysis using multivariate statistics. The same issues regarding educational differences are present in the coping report. In addition, the results are inaccurately reported: p=.06 is interpreted as 'very close to reach significance' and then interpreted as showing that one group used a particular strategy more than the other group.
Interpret and discuss the findings	Burden report: Inadequate exploration of findings. E.g., Aymaran CGs significantly more likely to feel incompetent than non-Aymaran CGs is interpreted as stemming from being a CG and belonging to an ethnic minority. Also refers to a significant different in civil status that was not shown in the results. Coping report: seems as though authors were keen to elaborate on Aymaran cosmology which may be related to the authors' overinterpretation of the use of spirituality as a coping mechanism among Aymaran CGs.
Present conclusions and recommendations.	Some limitations noted: small and uneven sample size, cross-sectional assessment. Some less meaningful limitations also noted: assessment environment could influence results (but no exploration of how).
Review conclusions	The methodological problems of the study and published reports undermine the reliability of the study's findings that Aymaran caregivers experience significantly more overall burden and feelings of incompetence than non-Aymaran caregivers, and use a similar range of coping strategies.